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ABSTRACT

Most older Americans who have impaired ability to function avoid institutionalization because of personal care and financial assistance received from family members or friends. However, there is a void in terms of national data on the magnitude of the phenomenon, the financial costs associated with providing care, the use of services especially developed for caregivers, and the effects of caregiving on employment. To fill the void, a national caregivers survey was conducted through a random sample of U.S. telephone households (N=754). The results indicated that about 7.8 percent of all households contained a caregiver, translating into about 7 million households. Three-quarters of the caregivers were women with an average age of 45. Reasons given for becoming a caregiver included living close (33 percent); no choice because no one else would do it (25 percent); and closer relationship with recipient than others (18 percent). Care recipients were most often mothers, grandmothers, fathers, or spouses. The average time commitment was 12 hours a week. Two-thirds of the caregivers provided assistance with one or more activities of daily living. Most caregivers used at least one support service, such as home health aides. The most mentioned caregiver needs related to information about developments in medicine and health care. Most caregivers surveyed had made lifestyle changes since becomming caregivers. (ABL)

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NATIONAL SURVEY OF CAREGIVERS

SUMMARY OF FINDINGS

CONDUCTED FOR:

THE AMERICAN ASSOCIATION OF RETIRED PERSONS
WASHINGTON, D.C. 20049

AND

THE TRAVELERS COMPANIES FOUNDATION
HARTFORD, CONNECTICUT 06183

OCTOBER, 1988

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BACKGROUND AND PURPOSE

- Approximately four-out-of-five older Americans who suffer from physical and/or mental disabilities which impair their ability to function avoid institutionalization because of personal care and financial assistance received from family members or friends.

- Such "caregiving" assistance involves activities related to managing a household and activities related to direct personal care of the individual.

- Prior research has suggested that caregiving creates physical, economic and emotional stresses for the care providers.

- Caregiving can be the equivalent of taking on a second job for those who work outside the home.

- There is still a void in terms of national data on:

  -- The magnitude of the phenomenon
  -- The financial costs associated with providing care
  -- The use of services especially developed for caregivers
  -- The effects of caregiving on employment

BACKGROUND AND PURPOSE (CONTINUED)

- To fill this void, a National Caregivers Survey was conducted among a random sample of U.S. telephone households.

- The National Caregivers Survey was sponsored by the AARP, with support from The Travelers Companies Foundation.

DEFINITION OF A CAREGIVER

- For the purpose of the National Caregivers Survey, a caregiver was defined as a person who provides unpaid assistance to a person 50 or older <u>within 12 months</u> of the time of the interview.

- This "assistance" may have consisted of either of the following:

  <u>2 Instrumental Activities of Daily Living (IADLs)</u>, including:

  -- Managing finances
  -- Grocery shopping
  -- Housework
  -- Meal preparation
  -- Transportation
  -- Administering medicine

  <u>OR</u>

  <u>One Activity of Daily Living (ADL)</u>, including:

  -- Dressing
  -- Bathing
  -- Toileting
  -- Feeding
  -- Help using a walker or wheelchair

OBJECTIVES OF THE NATIONAL CAREGIVERS SURVEY

- How many caregivers are there?
- Who are the caregivers?
- What responsibilities do caregivers have?
- What services do caregivers use?
- What types of assistance or services do caregivers perceive they need?
- What lifestyle changes have caregivers made to accommodate their responsibilities?
- What are the economic implications of caregiving?
- What are the implications for caregivers working outside the home?

METHODOLOGY

- Telephone surveys were conducted among 754 caregivers nationwide.
- The sample size chosen was large enough so that estimates derived from it have a margin of error of no more than ±5 percentage points.
- The survey sample selected for this study was ORC's National Probability Sample for Telephone Interviewing.
  - -- This source provides a random sample of U.S. telephone households generated from AT&T information.
  - -- It allows for projection to the population of caregivers.
- All residential households contacted were screened to determine the presence of caregivers as defined earlier.
- The person interviewed was the person in the household who was <u>primarily</u> responsible for providing caregiving assistance, either at the time of the interview or within the past 12 months.
- The target audience was care providers, not care recipients.

METHODOLOGY

- An initial call and up to three follow-up calls were made to each potentially qualified household.

- The 754 completed interviews were conducted between December 11, 1987 and January 25, 1988 from ORC's WATS facility in Middlesex, New Jersey.

- Survey procedures required that potential respondents be contacted on weekday afternoons and evenings as well as weekends.

  -- This allowed working caregivers an equal opportunity for participation.

HOW MANY CAREGIVERS ARE THERE?

- Estimates of the number of caregivers nationwide range from approximately 1.5 million to 7 million.

- Using the current survey definition and procedures, approximately 7.8 percent of all households contacted contained a caregiver.

- This translates to approximately 7 million U.S. households. Of these:

  -- 3.7 million (4.2%) contain <u>current caregivers</u>, persons giving care at the time of the interview

  -- 1.5 million (1.7%) contain <u>current</u> caregivers who provide two or more activities of daily living (ADLs)

FINDINGS -- WHO ARE THE CAREGIVERS?

- Caregiver Profile
  - -- Women (75%)
  - -- 45 years of age, on average
  - -- Married (66%)
  - -- Half work either full- (42%) or part-time (13%); one-fourth (27%) are not employed or homemakers; and 16% are retired
  - -- Primary caregivers (63%)
- Why become a caregiver?
  - -- Primary caregivers did not necessarily assume these duties by choice:
    - -- 33% did so because they were the only one who lives close
    - -- 25% say they had no choice, no one else will do it
    - -- 18% say they did so because they have a closer relationship than others with the care recipient

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Caregiver Profile

(Base)	Census*	Total (754)	Primary Caregivers (475)	Secondary Caregivers (247)
Sex				
Male	48%	25%	23%	28%
Female	52	75	77	72
Age				
Under 35	39%	28%	20%	42%
35 - 49	26	29	28	32
50 - 64	18	26	31	16
65 or Older	18	15	20	9
Median Age	36	45	49	38
Marital Status				
Married	63%	66%	66%	66%
Not Married	37	34	34	34
Children in Household				
Yes	38%	39%	34%	48%
No	62	49	51	43

CAREGIVER PROFILE
(CONTINUED)

(BASE)	CENSUS*	TOTAL (754)	PRIMARY CAREGIVERS (475)	SECONDARY CAREGIVERS (247)
CURRENT EMPLOYMENT				
FULL-TIME	53%	42%	38%	49%
PART-TIME	10	13	12	17
RETIRED	N/A	16	20	9
NOT EMPLOYED/HOMEMAKER	32**	27	29	22
HOUSEHOLD INCOME				
UNDER $10,000	19%	11%	13%	8%
$10,000 - $19,999	21	17	17	18
$20,000 - $29,999	18	19	19	21
$30,000 - $49,999	25	22	20	24
$50,000 OR MORE	18	10	10	11
MEDIAN INCOME	$26,000	$26,100	$25,700	$27,100

** TOTAL NOT IN LABOR FORCE

Caregiver Profile
(continued)

(Base)	Census*	Total (754)	Primary Caregivers (475)	Secondary Caregivers (247)
Primary Caregiver				
Yes	N/A	63%	100%	0%
No	N/A	33	0	100

* Source: CPR, p. 60, no.159, U.S. Census Bureau
CPR, p. 25, no.1022, U.S. Census Bureau
CPR, p. 60, no.161, "Consumer Income"

FINDINGS -- WHAT RESPONSIBILITIES DO CAREGIVERS HAVE?

- WHO ARE THE CARE RECIPIENTS?

  -- CAREGIVERS TYPICALLY CARE FOR THEIR MOTHER (28%), GRANDMOTHER (12%), FATHER (12%) OR SPOUSE (10%).

  -- THE CARE RECIPIENT AVERAGES 77 YEARS OF AGE; WITH ONE-FOURTH (24%) 85 OR OLDER, AND 13% BETWEEN THE AGES OF 50 AND 64.

  -- THE CARE RECIPIENT IS LIKELY TO SUFFER FROM A CHRONIC PHYSICAL DISABILITY WHICH RENDERS HIM OR HER HOUSEBOUND (58%)

  -- THE CARE RECIPIENT MOST OFTEN LIVES IN HIS OR HER OWN HOME WITHIN CLOSE PROXIMITY TO THE CAREGIVER (50%); WITH 37% SHARING A HOUSEHOLD.

FINDINGS -- WHAT RESPONSIBILITIES DO CAREGIVERS HAVE? (CONT'D)

- WHAT IS THE TIME COMMITMENT?
  - -- ON AVERAGE, CAREGIVERS HAVE BEEN PROVIDING CARE FOR 12 HOURS PER WEEK FOR THE LAST TWO YEARS.
  - -- ELEVEN PERCENT PROVIDE CONSTANT CARE; 28% PROVIDE CARE 8 HOURS OR LESS PER WEEK.
  - -- ONE-FOURTH (26%) HAVE BEEN PROVIDING CARE FOR LESS THAN ONE YEAR OR FOR 6 OR MORE YEARS (26%)
  - -- NEARLY ALL CURRENT CURRENT CAREGIVERS EXPECT TO CONTINUE PROVIDING CARE FOR AN INDEFINITE PERIOD OF TIME.

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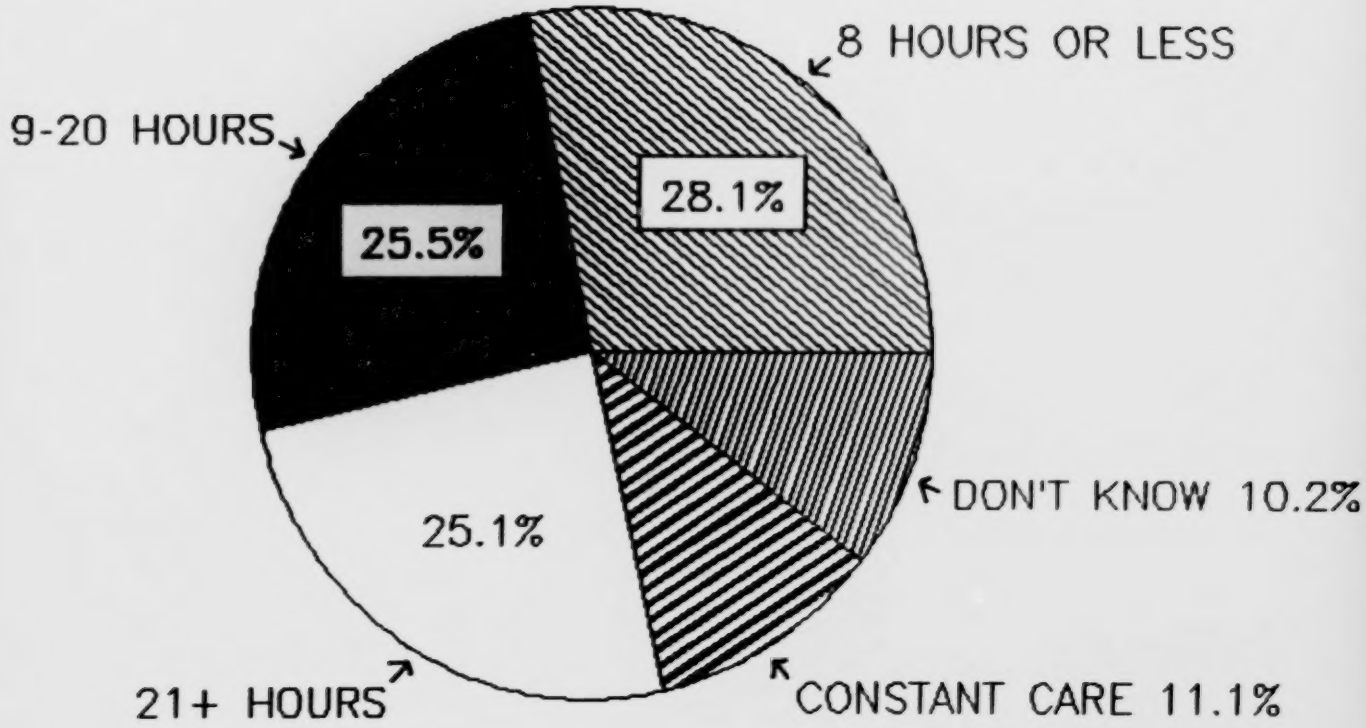
HOURS PER WEEK SPENT CAREGIVING



ALL CAREGIVERS

FINDINGS -- WHAT RESPONSIBILITIES DO CAREGIVERS HAVE? (CONT'D)

- WHAT SERVICES DO CAREGIVERS PERFORM?

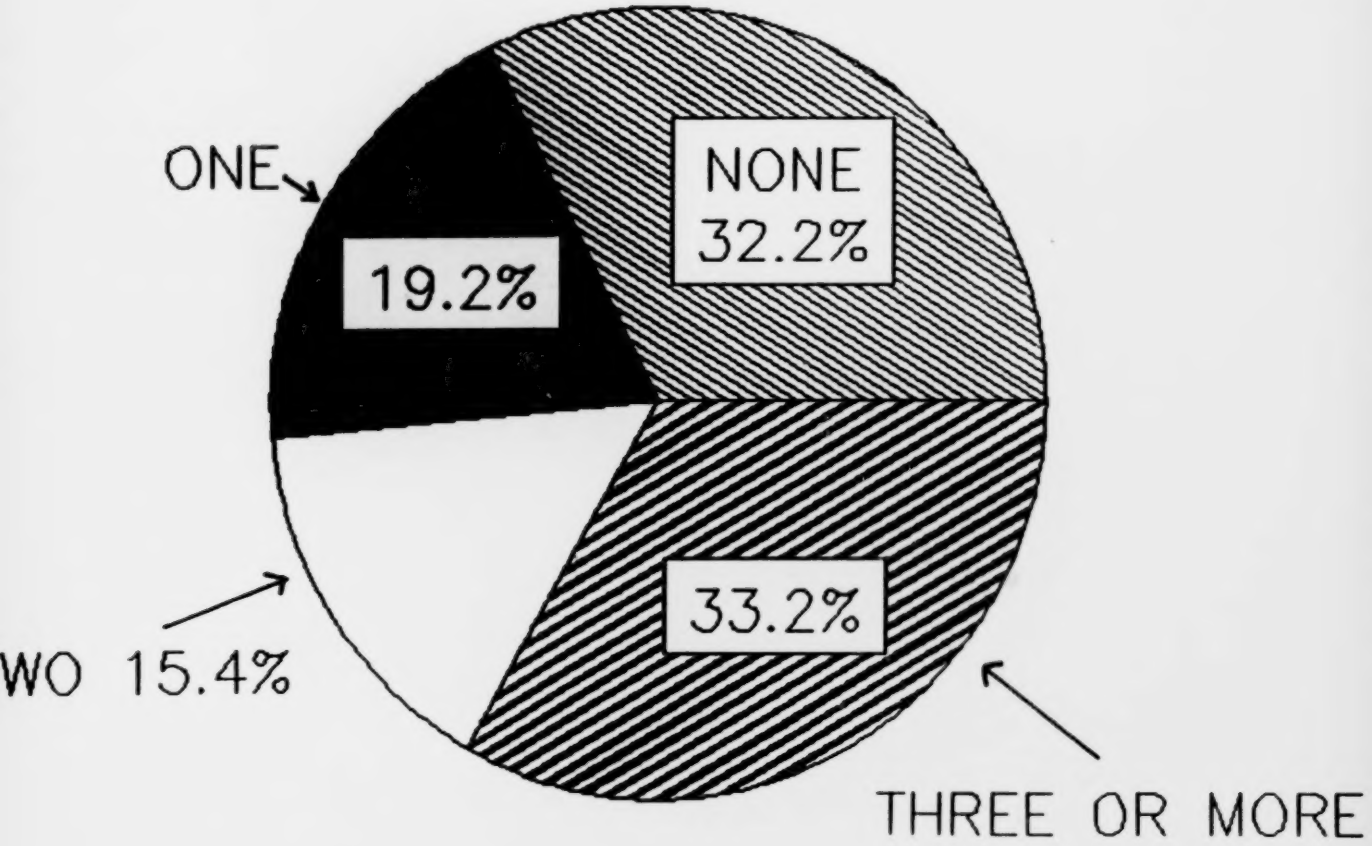
  -- TWO-THIRDS OF THE CAREGIVERS SURVEYED PROVIDE ASSISTANCE WITH ONE OR MORE ADLs (68%):

     -- 19% PROVIDE ONE ADL
     -- 15% PROVIDE TWO ADLs
     -- 33% PROVIDE THREE OR MORE ADLs

  -- CAREGIVERS MOST OFTEN PROVIDE ASSISTANCE WITH THE FOLLOWING ADLs:

-- WALKING	46%
-- DRESSING	41
-- BATHING	38
-- TOILETING	29
-- FEEDING	27

NUMBER OF ADLS PROVIDED



FINDINGS -- WHAT RESPONSIBILITIES DO CAREGIVERS HAVE? (CONT'D)

-- NEARLY ALL CAREGIVERS ASSIST WITH AT LEAST ONE IADL:

-- GROCERY SHOPPING	82%
-- TRANSPORTATION	79
-- HOUSEWORK	75
-- PREPARING MEALS	68
-- MANAGING FINANCES	65
-- ADMINISTERING MEDICINE	45

o CAREGIVING RESPONSIBILITIES EXIST ALONG A CONTINUUM OF CARE. AS AN OLDER PERSON'S NEEDS INCREASE, SO DOES THE NEED FOR MORE INTENSIVE CAREGIVING.

FINDINGS -- WHAT SERVICES DO CAREGIVERS USE?

- SIXTY-FIVE PERCENT OF ALL CAREGIVERS HAVE USED AT LEAST ONE SUPPORT SERVICE.

- NO SINGLE SERVICE HAS BEEN UTILIZED BY MORE THAN ONE-THIRD OF THOSE SURVEYED.

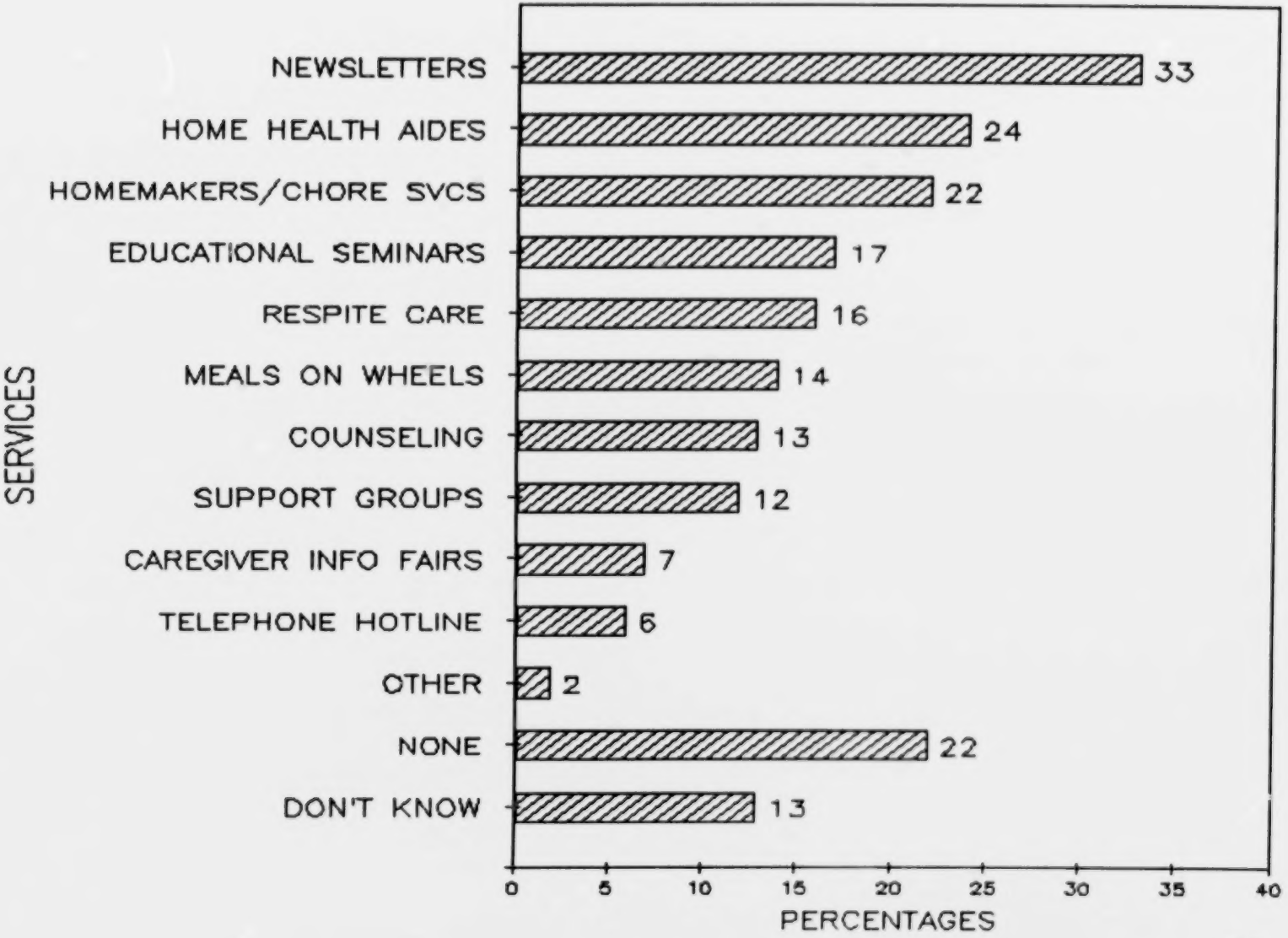
- CAREGIVERS MOST FREQUENTLY SEEK SERVICES WHICH PROVIDE THEM WITH ADDITIONAL INFORMATION OR HELP WITH HOUSEWORK.

- SERVICE PROVIDERS VARY BY TYPE OF SERVICE. HOWEVER, ASSISTANCE IS MOST LIKELY TO COME FROM COMMUNITY AGENCIES, FOLLOWED BY FRIENDS AND FAMILY.

  -- PAID SERVICES ARE USED PRIMARILY FOR HOME HEALTH AIDES OR HOMEMAKERS.

  -- RELIGIOUS ORGANIZATIONS AND EMPLOYERS DO NOT OFTEN FUNCTION AS SERVICE PROVIDERS.

UTILIZATION OF SERVICES



FINDINGS -- WHAT SERVICES DO CAREGIVERS USE? (CONT'D)

- CAREGIVERS MOST OFTEN ATTRIBUTE NON-UTILIZATION OF SERVICES TO A LACK OF NEED ON THEIR PART.
  - -- LACK OF AWARENESS OF AVAILABLE SERVICES IS THE SECOND MOST FREQUENTLY GIVEN REASON FOR NON-UTILIZATION.

FINDINGS -- WHAT TYPES OF ASSISTANCE OR SERVICES DO CAREGIVERS PERCEIVE THEY NEED?

- Caregiver needs relate primarily to:
  - -- Information about developments in medicine and health care (42%)
  - -- Help in dealing with bureaucracies to obtain services for the care recipient (39%)
  - -- Updates on federal and state legislation affecting their situation (35% to 38%)
- Secondary needs center on emotional support and respite:
  - -- Someone to talk to when they are overburdened (32%)
  - -- Some free time for a vacation (31%)
  - -- Someone with whom to share coping strategies (30%)

FINDINGS -- WHAT TYPES OF ASSISTANCE OR SERVICES DO CAREGIVERS PERCEIVE THEY NEED? (CONT'D)

- CAREGIVERS WHO BEAR A GREATER BURDEN OF RESPONSIBILTY GENERALLY PERCEIVE A HIGHER LEVEL OF NEED FOR SERVICES

  - -- PRIMARY CAREGIVERS
  - -- CONSTANT CAREGIVERS
  - -- CAREGIVERS WHO PROVIDE 3 OR MORE ADLs
  - -- CAREGIVERS WHO TAKE CARE OF SOMEONE WHO IS HOUSEBOUND, BEDRIDDEN OR CONFINED TO A WHEELCHAIR.

- PERCEIVED LEVEL OF NEED IS ALSO GREATER AMONG CAREGIVERS WITH CERTAIN DEMOGRAPHIC CHARACTERISTICS:

  - -- RACIAL MINORITIES
  - -- LOWER INCOME CAREGIVERS
  - -- UNMARRIED CAREGIVERS
  - -- CAREGIVERS WHO STILL HAVE CHILDREN LIVING AT HOME

FINDINGS -- WHAT TYPES OF ASSISTANCE OR SERVICES DO CAREGIVERS PERCEIVE THEY NEED? (CONT'D)

- A SPECIAL ANALYSIS WAS CONDUCTED AS A MEANS TO BETTER UNDERSTAND CAREGIVERS WITH RESPECT TO HOMOGENEITY OF NEEDS. RESULTS OF THIS SPECIAL ANALYSIS INDICATE THAT FIVE "NATURAL" CAREGIVER GROUPS EXIST, ARRAYED ALONG A CONTINUUM OF PERCEIVED NEED FOR SERVICES.

- GROUP A CAREGIVERS -- 24% OF ALL CAREGIVERS

  - PROVIDE LESS INTENSE CARE (43% PROVIDE NO ADLs) TO LESS DISABLED CARE RECIPIENTS
  - SPEND AN AVERAGE OF 9 HOURS PER WEEK ON CAREGIVING
  - ONLY 42% HAVE UTILIZED AT LEAST ONE SERVICE
  - NO PERCEIVED NEED FOR CAREGIVING SERVICES

FINDINGS -- WHAT TYPES OF ASSISTANCE OR SERVICES DO CAREGIVERS PERCEIVE THEY NEED? (CONT'D)

- o Group B Caregivers -- 24% of all caregivers
  - -- Equally likely to provide no ADLs (32%) or three or more (31%)
  - -- Similar to Group A Caregivers, but tend to be:
    - younger (38% are under age 35)
    - more likely to be men (34%)
    - more likely to be living alone (15%)
  - -- Spend an average of 9 hours per week on caregiving
  - -- 65% have utilized at least one service
  - -- Low level of perceived need for all services

FINDINGS -- WHAT TYPES OF ASSISTANCE OR SERVICES DO CAREGIVERS PERCEIVE THEY NEED? (CONT'D)

- o <u>GROUP C CAREGIVERS</u> -- 23% OF ALL CAREGIVERS
  - -- EQUALLY LIKELY TO PROVIDE NO ADLS (33%) <u>OR</u> THREE OR MORE (35%)
  - -- SPEND AN AVERAGE OF 14 HOURS PER WEEK ON CAREGIVING
  - -- LIKELY TO BE PAST PARTICIPANTS IN THE WORK FORCE
  - -- 73% HAVE UTILIZED AT LEAST ONE SERVICE; MODERATE TO HEAVY USERS OF NEWLETTERS AND EDUCATIONAL SEMINARS
  - -- MODERATE LEVEL OF NEED FOR CAREGIVING SERVICES, PARTICULARLY THOSE RELATING TO BEING KEPT UP TO DATE.

FINDINGS -- WHAT TYPES OF ASSISTANCE OR SERVICES DO CAREGIVERS PERCEIVE THEY NEED? (CONT'D)

- GROUP D CAREGIVERS -- 19% OF ALL CAREGIVERS
  - -- PROVIDE MORE INTENSE CARE TO HOUSEBOUND AND/OR BEDRIDDEN CARE RECIPIENTS. ONLY 25% PROVIDE NO ADLS; 41% PROVIDE THREE OR MORE ADLS.
  - -- DEMOGRAPHICALLY MORE LIKELY TO BE:
    - -- UNMARRIED (47%)
    - -- WOMEN (86%)
  - -- SPEND AN AVERAGE OF 15 HOURS PER WEEK ON CAREGIVING
  - -- 77% HAVE UTILIZED AT LEAST ONE SERVICE
  - -- HIGH LEVEL OF NEED FOR CAREGIVING SERVICES

FINDINGS -- WHAT TYPES OF ASSISTANCE OR SERVICES DO CAREGIVERS PERCEIVE THEY NEED? (CONT'D)

- o <u>GROUP E CAREGIVERS</u> - 10% OF ALL CAREGIVERS

  - -- PROVIDE INTENSE CARE (55% PROVIDE THREE OR MORE ADLs) TO MOST DISABLED RECIPIENTS.

  - -- THEIR CARE RECIPIENTS ARE MORE LIKELY TO BE HOUSEBOUND (74%) AND EITHER BEDRIDDEN (38%) OR CONFINED TO A WHEELCHAIR (38%).

  - -- DEMOGRAPHICALLY, THEY ARE MORE LIKELY TO BE:
    - -- WOMEN (83%)
    - -- MINORITIES (29%)
    - -- HAVE CHILDREN STILL LIVING AT HOME (50%)
    - -- UNMARRIED (47%)
    - -- LIVING IN LOWER INCOME HOUSEHOLDS (MEDIAN $19,400)

  - -- SPEND AN AVERAGE OF 19 HOURS PER WEEK ON CAREGIVING

  - -- 75% HAVE USED AT LEAST ONE SERVICE

  - -- NEEDIEST OF ALL CAREGIVERS; HIGH NEED FOR MORE OF ALL SERVICES

Service Utilization and Perceived Level of Additional Need for Services

	Caregiver Group				
	A	B	C	D	E
% Who Have Utilized At Least One Service (NET)	42%	65%	73%	77%	75%
% Who Perceive Additional Need by Category of Service					
General Background --	0%	0%	31%	88%	100%

Includes help in selecting a nursing home, information about finances, help dealing with bureaucracy, and general information about the aging process.

Service Utilization and Perceived Level of Additional Need for Services (continued)

	Caregiver Group				
	A	B	C	D	E
Updates -- Includes updates in state and federal legislation, information about health and medical developments, and a central place to go for information.	0%	0%	46%	80%	100%
Emotional Support & Respite - Includes someone to talk to and share coping strategies with, and free time for a vacation or to run errands.	0%	2%	32%	92%	100%

Service Utilization and Perceived Level of Additional Need for Services (continued)

	Caregiver Group				
	A	B	C	D	E
Housework --	0%	1%	21%	81%	100%

Includes help with light housework, heavy cleaning, shopping, ADLs, meal provision, and "daycare" while caregiver works.

FINDINGS -- WHAT LIFESTYLE CHANGES HAVE CAREGIVERS MADE TO ACCOMMODATE THEIR RESPONSIBILITIES?

- Three-fourths (72%) of the caregivers surveyed made lifestyle changes since becoming a caregiver:
  - -- Spent less time with their own immediate family (34%)
  - -- Paid less attention to their own health (33%)
  - -- Took fewer vacations (28%)

FINDINGS -- WHAT ARE THE ECONOMIC IMPLICATIONS OF CAREGIVING?

- TWO-FIFTHS (42%) OF THE CAREGIVERS SURVEYED REPORTEDLY INCURRED ADDITIONAL EXPENDITURES AS A RESULT OF CAREGIVING.

- THESE ADDITIONAL EXPENSES AVERAGED $117 PER MONTH OR 7 PERCENT OF MONTHLY INCOME:

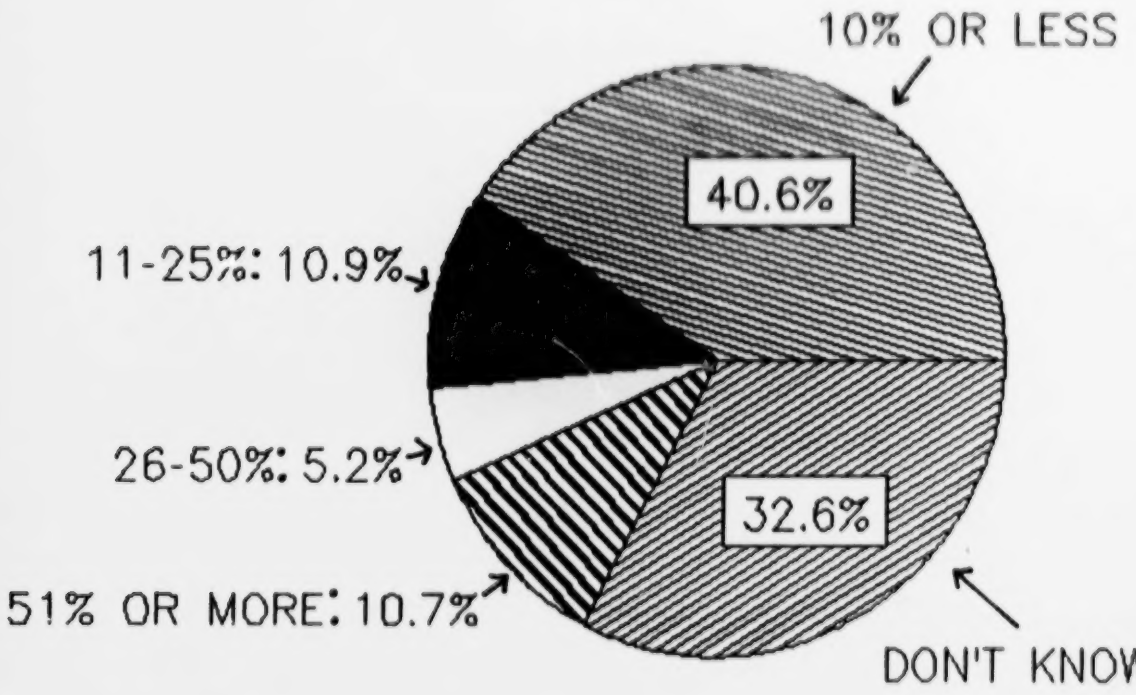
  -- 11% SPEND 51% OR MORE OF MONTHLY INCOME.

  -- 41% SPEND 10% OR LESS OF MONTHLY INCOME.

- AS A PERCENTAGE OF INCOME, CAREGIVING EXPENSES ARE GREATEST FOR THOSE WHO ARE:

  -- OVER 65
  -- NOT CURRENTLY EMPLOYED
  -- LIVING IN A HOUSEHOLD WITH AN ANNUAL INCOME OF LESS THAN $10,000
  -- PROVIDING CONSTANT CARE
  -- PRIMARY CAREGIVERS

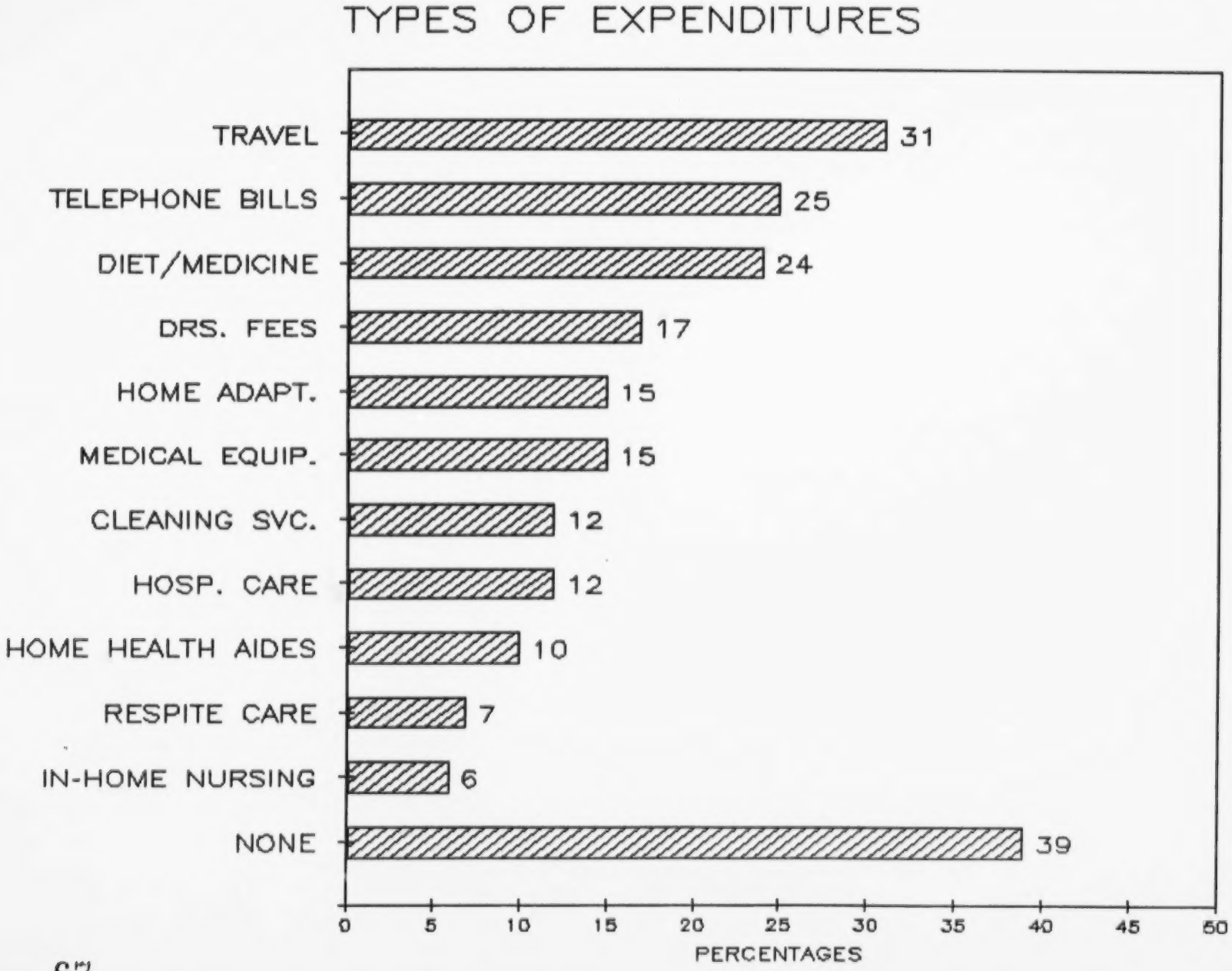
CAREGIVING EXPENSES AS A PERCENT OF MONTHLY INCOME



CAREGIVERS WHO REPORT ADDITIONAL EXPENDITURES

FINDINGS -- WHAT ARE THE ECONOMIC IMPLICATIONS OF CAREGIVING?

- ADDITIONAL EXPENSES ARE MOST FREQUENTLY INCURRED FOR:
  - -- TRAVEL (31%)
  - -- TELEPHONE BILLS TO KEEP IN TOUCH (25%)
  - -- SPECIAL DIETS AND MEDICINES (24%)
- MOST COSTLY OF ALL EXPENDITURES ARE:
  - -- HOSPITAL CARE ($275 PER MONTH, ON AVERAGE)
  - -- IN-HOME NURSING CARE ($238 PER MONTH ON AVERAGE)


TYPES OF EXPENDITURES
TRAVEL
TELEPHONE BILLS
DIET/MEDICINE
DRS. FEES
HOME ADAPT.
MEDICAL EQUIP.
CLEANING SVC.
HOSP. CARE
HOME HEALTH AIDES
RESPITE CARE
IN-HOME NURSING
NONE
31
25
24
17
15
15
12
12
10
7
6
39
0
5
10
15
20
25
30
35
40
45
50
PERCENTAGES

FINDINGS -- WHAT ARE THE IMPLICATIONS FOR CAREGIVERS WORKING OUTSIDE THE HOME?

- MORE THAN ONE-HALF (53%) OF ALL CAREGIVERS ARE EMPLOYED OUTSIDE THE HOME.

- WORKING CAREGIVERS SPEND AN AVERAGE OF 10 HOURS PER WEEK ON CAREGIVING:

  -- 34% SPEND 8 HOURS OR FEWER
  -- 6% PROVIDE CONSTANT CARE

- WORKING CAREGIVERS (ESPECIALLY FULL-TIME EMPLOYEES) TEND TO PROVIDE LESS INTENSE CARE TO LESS DISABLED INDIVIDUALS.

- NEARLY TWO-FIFTHS (38%) OF WORKING CAREGIVERS HAVE EITHER LOST TIME FROM WORK OR COME IN LATE AS A RESULT OF CAREGIVING DUTIES.

  -- 20% HAVE LOST BENEFITS AS A RESULT.

CONCLUSIONS & IMPLICATIONS

THIS RESEARCH REPRESENTS THE FIRST ATTEMPT AT A NATIONAL SURVEY EXAMINING THE CAREGIVING CONTINUUM. THE RESULTS HAVE IMPORTANT IMPLICATIONS PARTICULARLY FOR FURTHER RESEARCH, EDUCATIONAL EFFORTS AND PUBLIC POLICY. FOLLOWING ARE THE QUESTIONS AND SIGNIFICANT FINDINGS THAT EMERGE FROM THIS DATA WITH RESPECT TO:

- SERVICE UTILIZATION
- COSTS OF CAREGIVING
- WORKING CAREGIVERS

SERVICE UTILIZATION

THE RESEARCH PROVIDES A SNAPSHOT VIEW OF THE CAREGIVING CONTINUUM. AS THE OLDER PERSON'S NEEDS INCREASE, SO DOES THE NEED FOR MORE INTENSIVE CAREGIVING. ALSO, IT APPEARS THAT CAREGIVERS DO NOT PERCEIVE A STRONG NEED FOR SERVICES UNTIL THEIR RESPONSIBILITIES REACH CRISIS PROPORTIONS.

CONSEQUENTLY, PROGRAM PLANNERS MAY WANT TO BEGIN IMPLEMENTING STRATEGIES DESIGNED TO RAISE PUBLIC AWARENESS ABOUT THE CAREGIVING ISSUE EMPHASIZING THE NEED FOR AND VALUE OF PLANNING AHEAD. PLANNERS MAY ALSO WANT TO MAKE HELPFUL INFORMATION AVAILABLE TO PERSONS WHO HAVE NOT USED THEIR SERVICES, EMPHASIZING THE VALUE OF SOME SUPPORT BEFORE A CRISIS LEVEL SITUATION DEVELOPS. IN ADDITION, AGGRESSIVE OUTREACH EFFORTS TO IDENTIFY THE MOST OVERBURDENED CAREGIVERS WHO PERCIEVE A HIGH NEED FOR ALL SERVICES WOULD BE APPROPRIATE.

SERVICE UTILIZATION (CONTINUED)

ADDITIONAL INFORMATION IS NEEDED REGARDING THE CONTINUUM OF CARE AND THE POINT AT WHICH A CAREGIVER REACHES OUT FOR SUPPORT. FURTHER CLARIFICATION IS ALSO NEEDED REGARDING THE "PERCEPTION THAT CAREGIVERS DON'T NEED SERVICES." SPECIFIC RESEARCH QUESTIONS MAY INCLUDE:

- WHAT IS THE MOST EFFECTIVE WAY OF GETTING INFORMATION TO CAREGIVERS?
- HOW CAN CAREGIVERS BE PERSUADED TO PLAN BEFORE A CRISIS OCCURS?
- THIRTY-NINE PERCENT OF CAREGIVERS SAID THEY NEED ASSISTANCE DEALING WITH THE SERVICE BUREAUCRACY. HOW CAN THE SERVICE SYSTEM BE MODIFIED SO THAT CAREGIVERS CAN OBTAIN NEEDED ASSISTANCE?
- TWENTY-EIGHT PERCENT OF CAREGIVERS IN THIS STUDY ARE 35 YEARS OF AGE AND YOUNGER. WHAT EFFECT DOES CAREGIVING HAVE ON THIS GROUP? AS MOST RESEARCHERS HAVE ASSUMED THAT CAREGIVERS ARE MUCH OLDER, THERE IS A LACK OF DATA ON YOUNGER PERSONS IN THIS SITUATION.

COSTS OF CAREGIVING

THE RESEARCH PRESENTED HERE IS ONE OF THE FIRST ATTEMPTS TO INVESTIGATE THE ECONOMIC IMPLICATIONS OF CAREGIVING. ALTHOUGH THE INFORMATION REPORTED MUST BE INTERPRETED CAUTIOUSLY BECAUSE THE FINANCIAL DATA ARE BASED ON ESTIMATES, IT REPRESENTS A FIRST STEP. FURTHER CLARIFICATION IS NEEDED ON THE FINANCIAL COSTS ASSOCIATED WITH CAREGIVING. THE CURRENT DATA, HOWEVER, DO RAISE SOME INTERESTING QUESTIONS FOR PUBLIC AND PRIVATE POLICY.

PERHAPS POLICY MAKERS MAY WANT TO TAKE A LOOK AT HOW "DEPENDENT" IS DEFINED. AS ONLY 37% OF CAREGIVERS IN THIS STUDY SHARE A HOUSEHOLD WITH THE OLDER PERSON, SHOULD PLACE OF RESIDENCE BE A CRITERIA FOR DEPENDENT-CARE TAX CREDITS AND OTHER BENEFITS? AS MANY CAREGIVERS ARE MAKING SIGNIFICANT FINANCIAL CONTRIBUTIONS TOWARD THE CARE OF AGING LOVED ONES, SHOULD CAREGIVERS BE COMPENSATED PERHAPS THROUGH A TAX INCENTIVE OR THROUGH AN EMPLOYER-SPONSORED BENEFIT WHICH WOULD COVER THE OLDER PERSON? AGAIN, FURTHER RESEARCH IS NEEDED BEFORE THESE ISSUES CAN BE ADDRESSED.

WORKING CAREGIVERS

IN THE AREA OF EMPLOYMENT AND CAREGIVING, CLEARLY ADDITIONAL RESEARCH IS NEEDED ABOUT THE EFFECTS OF CAREGIVING ON WORK PARTICULARLY AS IT PERTAINS TO LOSS OF BENEFITS AND TIME LOST FROM WORK. AS THE NUMBER OF WORKING CAREGIVERS IS EXPECTED TO INCREASE, IT MAY BE WISE FOR COMPANIES TO BEGIN EXPLORING HOW TO ASSIST EMPLOYEE CAREGIVERS IN ORDER TO AVOID DISRUPTIONS IN PRODUCTIVITY.

CONCLUSIONS

THERE ARE MANY OTHER ISSUES RELATED TO CAREGIVING THAT NEED TO BE EXPLORED. THE CURRENT RESEARCH SERVES AS A BEGINNING AND SHEDS SOME LIGHT ON SEVERAL ISSUES. PERHAPS MORE IMPORTANTLY, IT RAISES MANY CRITICAL QUESTIONS FOR FURTHER RESEARCH, PUBLIC POLICY AND PROGRAM PLANNERS.

CAREGIVING IS -- OR WILL BE -- A REALITY FOR MOST AMERICANS. IT AFFECTS OUR FAMILIES, OUR WORKPLACES AND OUR COMMUNITIES. THE ASSISTANCE PROVIDED BY CAREGIVERS HAS ITS REWARDS BUT IT CAN ALSO CREATE BURDENS. IT IS HOPED THAT THIS RESEARCH AND FUTURE EFFORTS WILL HELP DEVELOP CREATIVE AND EFFECTIVE PRIVATE AND PUBLIC INITIATIVES THAT TRULY SUPPORT CAREGIVERS.

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